



# STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR  
PERSONS WITH DISABILITIES

60B WESTON STREET, HARTFORD, CT 06120-1551

JAMES D. McGAUGHEY  
Executive Director

Phone: 1/860-297-4307  
Confidential Fax: 1/860-297-4305

Testimony of the Office of Protection and Advocacy for Persons with Disabilities  
before  
The Program Review and Investigations Committee  
Regarding  
Planning for the Needs of Aging Individuals with Developmental Disabilities

Presented by: James D. McGaughey  
Executive Director  
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Thank you for this opportunity to comment on the direction of the study you are conducting into this issue, and thanks to your staff for assembling so much information and presenting it so clearly in their briefing report. Through this study the Committee is focusing on to an issue of major importance to thousands of individuals and families in Connecticut – one that tests not only our ability to analyze and plan and budget, but also our sense of basic fairness and justice.

Our Office's interest in this area stems from two sources: 1) our experience advocating for individuals and families who are getting older and who wish to avoid (or are seeking to leave) long term care institutional placements; and 2) what we have been learning as the host agency for the State's Fatality Review Board for Persons with Disabilities (FRB). The FRB, was created by an executive order in 2002 to independently review and pursue selected investigations into deaths of people with disabilities, focusing on the deaths of people who receive services from the Department of Developmental Services. It is composed of physicians, law enforcement representatives and providers who volunteer their time in the hope that by better understanding how and why people die we can improve care for those still living.

Over the past several years the FRB has become increasingly concerned about people with mental retardation who have been living in nursing homes when they died. Of the 1116 people whose deaths were reviewed by the FRB between January 1, 2002, and December 31, 2007, 357 (32%) were living in nursing homes when they died. Part of the concern involves the quality of care in certain facilities. We have seen some instances where neglect on the part of a nursing home clearly contributed to an individual's death.

But, even nursing homes that provide generally good health care are not really good places for most people with developmental disabilities to be living. We know from the cases where we have conducted investigations that the providers who had supported people prior to the illness or injury that led to their admission to a facility would, in many cases, have liked to continue to do so but lacked the resources or programmatic flexibility necessary to do so. So the FRB has become interested in knowing how many people with mental retardation were winding up in long term care facilities, and why. With help from the nursing program at Quinnipiac University we are in the process of trying to sort out some of the answers to these questions. As we discussed with your staff when they interviewed us, we hope to have data to share with them by next month.

But even without data analysis, we do know some things just from the investigations we conduct. For instance, we know that nursing home admission often follows an injury or illness that requires hospitalization. Not infrequently, the person has experienced some progressive decline prior to the hospitalization. Wherever the person had been living before going to the hospital – a group home, an apartment program, a family home – was not set up to meet their needs for increased care, sometimes because the person's mobility had become impaired and their home was not physically accessible, and sometimes because the program was not staffed to provide the level of support the person now needed. Of course similar things also happen to people who do not have developmental disabilities. But for people with developmental disabilities, placement into a facility may be an even more disorienting emotional wrench and can produce unique risks. It often means an abrupt end to supports and relationships that may have taken a long time to sort out and that are essential for interpreting the person's needs – particularly when the person is not well able to articulate them for him or herself. This phenomenon is compounded by hospital discharge practices, which often result in nursing home placements that are some distance from whatever community support networks the person may have, and by DDS's practice of re-assigning case managers and discontinuing monitoring of the person's healthcare once they are admitted to a nursing home.

We also know that not everyone who is admitted to a nursing home comes from a supported residence – some are placed directly by their families, often because family care-givers died or become disabled themselves. At least some of these people we know who have gone to live in long term care facilities explored obtaining residential supports through DDS, but their situations did not meet the criteria to be considered emergencies. So, they were placed on waiting or planning lists. Our advocates are currently working with a family member who grew so concerned that her elderly parents were no longer able to take care of her brother's basic needs that she arranged his admission to a nursing home as a stop gap measure – only to find that because he was now living in a "safe" place, his placement priority status is much lower than it would have been had he continued to live with his elderly parents. We are hoping that when the Money Follows the Person application process opens for DDS clients – which hopefully will be soon - we will be able to help this man onto that list. But, in the meantime, this family – which has always stood by him, has included him in everything, has been committed to doing the right thing by him for the last 62 years, and has never asked for any help from anyone – is

left wondering whether he will spend his last days defined as a “patient” in a nursing home, where he is quite aware that he is surrounded by people who are chronically ill, and where he becomes understandably upset every time one of the older residents dies.

Based on our Office’s experience, I think the issues outlined for further inquiry in Section V of the staff briefing paper are right on point. My only suggestion would be to add a question regarding how well the identity and needs of people living in long term care facilities are being tracked by DDS. Anecdotally, we know of people who were known to DDS at one time, who were admitted to nursing homes, but who have no DDS case manager or whose case manager has not visited for several years. We also know that facilities often fail to inform DDS when one of its clients dies or experiences a major change in health status. So the information DDS currently has regarding people living in these facilities may not be complete.

In the long run it seems clear that additional program development will be required to meet the needs of people who are aging. It also seems fairly clear that most people prefer options that fall under the category of “aging in place”. In fact, our Office is participating with our partners in the Developmental Disabilities Network in a symposium that will be held in October to help develop a fuller sense of what “aging in place” may mean for people with developmental disabilities. In developing more targeted supports, therefore, I would hope that both the Department of Developmental Services and the General Assembly will seek to build on the existing network of community programs and providers rather than investing in specialized congregate facilities. Doing so can help maintain relationships and the sense of belonging that people seek, and may also prove to be the most economical approach.

Thank you for your attention. If there are any questions, I will try to answer them.